




Illustrated Stories of Severe Asthma: A Case Study

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ABSTRACT

This is a critical account of a project in which Illustration and oral history students developed demonstration graphic medicine artworks in response to interviews with people with severe asthma. The people with severe asthma collaborated with the students to produce the illustrated narratives as comics. The graphic medicine outputs tell the stories of how two lives changed due to new medications. This paper uses the student projects as a case study to explore the novel methodological approach. The comics demonstrate a shift in narrative authority towards the interviewees and the reader, and away from the artists who had no medical expertise or the medical experts who had no lived experience of the disease. Vernacular medical knowledge was used to capture unique perspectives, and students' active participation in the interviews was of critical significance in providing new insights into the lived experiences of medical intervention. The paper reflects on the visual and narrative techniques employed by the students to communicate these stories, the value of this process for students and the possibility of using this approach within a formal research study.

All expressed significant value from the experience.

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INTRODUCTION

Prior collaboration starting in 2017 has led to the formation of a network of artists, historians, and scientists called 'Fresh Air World' working together to create illustrated products to enhance health messaging and transform global opinion and thinking about the risks of air pollution (Kilburn et al., 2023). The projects commenced by adapting participatory action research (PAR), and co-creation methods to foster collaborative work with a diverse range of partners. Students created educational materials about household air pollution in various formats; digital, animation, posters and games that are used widely in Africa and globally (Jones et al., 2019; Nantanda et al., 2019).

In 2020, a new partnership formed with researchers specialising in the treatment of severe Asthma. Four students were invited to take part as participants for a project which aimed to use oral history interviews to create demonstration illustrated narratives based on the personal stories of people with severe asthma. The interviews and graphic medicine comics were to be undertaken and developed within taught modules by students of oral history and illustration at University of Plymouth. The project aim was to offer students an example of working in the professional field whilst providing a case study for how graphic medicine methods could effectively be employed within transdisciplinary arts, health & humanities research. The project was a student participatory project involving novel methods of collaboration across university faculties. Ethical approval for the student projects was acquired according to the Faculty of Arts, Business, and Humanities ethics regulations.

Project team leadership reflected the disciplinary backgrounds that formed the collaboration: health with clinical research expertise and specialist reputations in severe asthma – Prof. Rupert Jones, Dr Joseph Lanario; global health - Alice Inman; illustration – John Kilburn; and history and memory with a focus on oral history – Dr Darren J. Aoki. All Project leaders have participated in a range of collaborative initiatives, for example, Jones, Inman, and Kilburn within 'Fresh Air World', and Kilburn and Aoki in the development and application of 'talking history<>seeing history' (hereafter THSH) community-based projects around the southwest UK. With reference to Kilburn's and Aoki's THSH collaborations, all have involved the recruitment of undergraduate and postgraduate students.

Partnerships with the Faculty of Health and the School of Humanities have required the study and application of graphic medicine approaches. By testing these methods as part of the curriculum, this helps us achieve our aim of providing students with the skills to create work that can engage and communicate to mass audiences (Gannon and Fauchon, 2021) and to "say or do something mature or relevant" (Male et al., 2016, para. 18). Interdisciplinary work increases opportunities for impact because the work will be shared via multi-disciplinary academic and professional networks. Student work from these partnerships have been used within international research projects, published, licensed by pharmaceutical companies, and nominated for international awards. These successes have inspired other students to work on their own autoethnographic, oral history, and personal health narratives contributing to a supportive student and alumni comics community that engages with national and international events and local communities. Students gain practical and professional understanding of working on an academic study whilst being supported in a safe environment. This project recreated a professional interdisciplinary working situation that promotes illustration practice as integral to creative research processes rather than *merely illustrating* (Lord, 2023) or making other people's research look pretty.

This critical account explores how student engagement in the research process opened methodological and, in turn, conceptual opportunities, enhancing the Participant Action Research framework in unexpected ways. Firstly, students as non-medical experts, shifted narrative authority to participants to generate testimony that was affectively, descriptively, and medically rich, while also illuminating ethical questions concerning treatment. Secondly, the illustration students had little knowledge of graphic medicine as a subject area and only developing or foundational skills or experience of making comics. The students benefited from the freedom and 'permission' to create unique, subjective, and authorial interpretations of the interviews supported by the interdisciplinary team. Their developing artistic identities can be seen as both central and at the margins of the work. The outputs and impact support arguments for the value of this approach for students and for advocating for the potential of authorial illustration methods within transdisciplinary research.

CONTEXT

People with severe asthma have life-threatening asthma attacks, relentless symptoms, and constant need for medication. Oral steroids have serious adverse effects including weight gain, osteoporosis, and muscle weakness (Hyland et al., 2015, Volmer et al., 2018). In addition, they may suffer from severe psychological impacts including anxiety, depression, and social isolation, with guilt and feelings of failure contributing to low self-worth. In recent years, novel biologic treatments have revolutionised the treatment of some people (Agache et al., 2021). While some patients have little or no benefit from biologics, others see their asthma go into complete remission (super-responders) (Rupani and Hew, 2021). Improvements are regularly described by super responders as life changing, as detailed in a qualitative study by Lanario et al., 2022 (Lanario et al., 2022). In reflecting on this study, Lanario expressed how challenging it was to convey quite how profound and wide ranging these were using words. Normally medicines are evaluated using scientific endpoints such as number of asthma attacks, lung function tests, and other physiological markers. The personal perspective is largely absent. Personal narrative of the impact of disease and its treatment is an underused resource for explaining the benefits of novel treatments with health professionals and patients.

The major benefits of biologics that many people report remain poorly understood by patients, clinicians, and regulatory authorities. While qualitative, verbal, and written testimony data is helpful, less attention has been paid to how these benefits might be deployed in ways that promote comprehension and grab attention more compellingly. Comics have many advantages for health messaging including crossing literacy barriers, being easily disseminated by social media and encouraging compassion by showing the human dimension to illness whilst allowing us to process, reflect on, and understand our experiences (Green and Myers, 2010). Various studies have reported on the benefits of comics for communicating health messages (Tekle-Haimanot et al., 2016, Farinella, 2018, McNicol, 2015, McNicol, 2014) or the communication of science (Li et al., 2023, Farinella, 2018) but there is little data on how words and pictures have been used to communicate the effectiveness of novel treatment methods to patients and clinicians. Examples can be found in the archive of Covid-19 comics on the Graphic Medicine website (Czerwiec et al., 2023); during the pandemic, new vaccines were introduced, quickly and with significant controversy and suspicion and this archive contains examples of artists and scientists working together to create comics as a method of mitigating misinformation and promoting the benefits of new vaccines for all. Academic studies support the value of comics as an

informative medium for providing information on immunisations if the target audience is considered carefully (Muzumdar and Nania, 2015, Muzumdar and Pantaleo, 2017) but the examples created for these studies are instructional/didactic and do not represent a person-centred approach. For children, using superheroes to promote vaccines might be an effective method. Muscio's 2023 study into role of science and technology in Marvel superhero comics highlights that superhero comics can influence perceptions of science and technology and concludes that "scientists need to do much more to collaborate with mass media outlets, to communicate their discoveries in more accessible terms and to reduce people's fears and inspire trust and hope in new discoveries" (p. 9).

There is a long history of comics as part of the visual culture of medicine (Callender et al., 2020) and 'Graphic medicine' is now a well-established term referring to comics or sequential narratives that illustrate stories related to health. Increasingly, illustration students, artists, and comic makers have embraced the 'Graphic medicine' format resulting in a rise of self-published and small press publications. Examples are often championed by web-magazines or blogs such as the influential Broken Frontier website in the UK (Oliver, 2023) and are sold via artist websites, social media, illustration and small publishing fairs or events. Examples of graphic medicine are often based on ethnographic research, or in the form of educational information or instructions as sequential images. Sometimes the term may be used to refer to stand alone images, such as graphic signage without a sequential element, that might be found in a clinical setting. Since 2010 annual conferences have taken place inviting papers and academic discourse on the subject (Czerwicz et al., 2015). Graphic medicine comics are widely published, and the Graphic Medicine website includes an extensive collection of comics covering a wide spectrum of mental and physical illness.

A prevailing impression of comics may be that they are just for kids (Myers and Goldenberg, 2018) but this preconception can be unhelpful when promoting comics as a serious tool for communicating health messages. Studies have shown that images or pictograms can: significantly improve health outcomes by improving patient inhaler techniques (Almomani et al., 2018); support comprehension of asthma control status and promote self-management intentions in patients with persistent asthma (Arcia et al., 2019) and support paediatric receptiveness to asthma action plans (Pascuet et al., 2010, Roberts et al., 2009), but most adult patients are unlikely to have been given a comic book from a doctor (Ashwal and Thomas, 2018) and may need to be reassured as to the accuracy and relevance of the materials.

Unsurprisingly, there are various educational asthma comics aimed at younger audiences such as *Iggy and the Inhalers* (Thomas, 1993), *The Asthma Wizard* (Davis and Mahomet, 2013), or *Medikidz* (Renfrew, 2015). Single image narratives, short editorial comics and memes are commonplace, often poking fun at the illness and its treatments and sometimes making use of well-known characters from popular culture; an example is an image of the Incredible Hulk with the caption 'You won't like me when I'm on prednisone' (prednisone is a corticosteroid medication). In the mainstream Marvel Comic Universe there is the example of the Asthma Monster (1987), a villain who battles with Captain America and uses an 'aller-gun' to cause asthma in non-asthma sufferers. Examples of graphic medicine about pulmonary disease for adults can be found in long-form graphic narratives such as *Things to Do in a Retirement Home Trailer Park* by Aneurin Wright (Wright, 2012), that centres on a person with emphysema nearing the end of life, and *Mom's Cancer* by Brian Fies (Fies, 2006) which recounts his mother's battle with lung cancer and its metastasis to the brain. The popularity of these titles suggests a strong

demand for graphic works of this nature.

HOW THE PROGRAMME WAS CONDUCTED

Stage 1: Recruitment, training and preparation

At the start of this project four paid student participants were recruited from undergraduate and postgraduate programmes of study at the University of Plymouth. One student represented the MA Heritage Theory and Practice, another was studying MA Illustration and two were undergraduate Illustration students. The students were approached because they had shown aptitude in previous modules and growing expertise in heritage practice and/or the incitement and artistic representation of memory. Funding these internships was the University of Plymouth Arts-Health Collaboration Fund, an initiative providing seed-corn funding to promote inter-disciplinary collaboration between the Faculty of Arts, Humanities and Business and the Faculty of Health.

Recognising the limited interview experience and lack of specialist knowledge of the students, project team leaders constructed an intensive series of workshops and seminars. This included formal Oral History training through participation in the Centre for Oral History and Tradition-University of Plymouth Workshop¹ (2 March 2022) and follow-on workshops to co-develop interview questions lists and ethics documents. Seminars introduced the interns to severe asthma research and clinical therapies and students were supported through a series of meetings including post-interview debriefing and on-going tutorials. Through the taught illustration programme, students received training in visual thinking and live scribing to offer strategies for interpreting the oral testimonies, and a series of lectures and taught sessions on making and understanding comics, including visiting talks by practicing artists and publishers working on biographical projects. When critically analysing the project, we recognised that these limitations – especially as regards who owns medical knowledge – opened a unique opportunity regarding authority (and ownership of the story).

Stage 2 – Oral history interviews

Six people living with severe asthma in Devon, UK were invited to take part. A pamphlet was created to give information on the project. Two individuals agreed to take part in the project. There was a pre interview conversation about the details of the project, and then the student interviews commenced. The individuals gave their personal perspective on the experiences of a particular asthma medication especially within their wider remembered life story of living with asthma. The participants knew the interviewers would be a postgraduate student in oral history and a student on either an MA or BA (hons) Illustration programme. The participants were informed that this personal narrative would be visualised creatively by illustrators present in their interview, albeit without any uniquely identifying features included to protect confidentiality. Informed by our co-creative approach and to ensure that participants' authority over their stories was fully recognised, the participants were told they would be shown the results and given the opportunity to comment. The recordings were private, and the participants were informed that they would be able to consent, or withhold the final visual product being distributed outside the project team. Two participants gave informed consent according to

¹ Aoki is a member of the Centre for Oral History and Tradition Executive Committee. Based in the University of Lethbridge, the COHT is one of Canada's leading specialist academic research and community outreach organisations promoting and innovating the use of oral history. Aoki is co-developer of the UK iteration of the COHT's Beginner Oral History Workshop.

our project's ethical protocol approved by the University of Plymouth ethics system, and the process started with audio recorded semi-structured interviews.

The Oral history interviews explored individual memory within the framework of experiences of their asthma before and after treatment. According to Kilburn et al. (2022),

There was an emphasis on how change might be narrated in various registers: verbal recollection intersecting with visual imagination; articulation of emotions and especially key moments of crisis, overcoming adversity, and aspiration; impact on interpersonal relationships; personal sense of self-worth and value; and the identification of core life story narrative themes and images. (Methods section)

The students' active participation in the interviews was of critical significance to inform their understanding and the development of the graphic medicine outputs. In addition to hearing what was said, they witnessed how a memory was recollected and articulated, in verbal as well as embodied and emotional ways. As part of student training, debriefing sessions identified and reflected on core elements of the interviews in student-centred discussions, while also checking in on how students felt with attention specifically on difficult memories they may have encountered.

Now, let us turn specifically to discussions around the form of oral history that was employed. A loose, life-story approach was adopted, involving semi-structured audio-recorded interviews of around 60 minutes. According to Anna Sheftel who worked with survivors of atrocity in the Bosnian-Herzegovina war, this approach envisages the oral history interview as "collaborative conversations [that] should ideally generate narratives that do justice to the interviewee's experience without overly constraining it" (Sheftel, 2018, p. 290). Oral history, as Calabria and Bailey observe, is a 'natural ally' of Participant Action Research (Calabria and Bailey, 2023). This approach invites participants to define their past as they see it now, in what might be referred to as the generation of 'autobiographical memory', that is, the instantiation of past experiences and understandings of oneself through the lens of the present, a construction that privileges self-construction and presentation according the full range of their priorities and values at the time of the interview engagement (Aoki, 2019, Josselson, 2009, Abrams, 2010). This quantum memory-moment of the past in the present was critical to the approach because it opened the possibility of distancing participants from the most immediate moments of suffering, distress, fear, and trauma induced in the symptoms and condition of pre-treatment severe asthma. In other words, the project sought to understand therapy efficacy in ways that might generate a more holistic view of the participant's life, not necessarily or automatically defined by severe asthma.

There is a long tradition of oral histories being used to create comics. Oral narratives tend towards the collective saga recreated by common consent, (Portelli, 1991, Buhle, 2007) and this supports the applied approach of using oral histories to capture personal narratives and using these as the starting point to build a holistic understanding of health. Medical illustrator Merlin Evans (*Drawn to Medicine*) describes a similar approach as "radical listening" (2024, para. 3). The co-creative approach which informs the interviewee-interviewer relationship was extended to the inter-disciplinary and creative collaboration. Comics made in this way could be seen as more than a detailed narration of actual events but a collaborative exploration or "participatory illumination" (Waldron

and Braund, 2020, p. 218). They represent the memories of the storyteller, but also the intention of the artists, historians and academics, and their understanding of subject and context. 'Person-centred' not only forms a key methodological framework within the oral-visual conversation that our approach – specifically 'talking history<>seeing history' (hereafter THSH) – has developed and applied. It is also an ethical position that requires us to interrogate critically different participants positions as specialists (or students with developing specialisms) representing diverse disciplinary backgrounds coming together in multi-disciplinary collaboration.

**“Human beings do not belong to any one field of scholarly inquiry”
~ Alessandro Portelli (Portelli, 1991, p. 1)**

An advantage of bringing illustrators and oral historians together to collect and illustrate personal health narratives is the broad range of expertise that may complement, or indeed complicate the collaboration. This approach could lead to new insights on successful and impactful methods of graphic medicine practice. In *The Death of Luigi Trastulli, and Other Stories: Form and Meaning in Oral History*, Alessandro Portelli reflects that a consequence of the primacy of field work, and inductive approaches, is that oral historians tend to develop a heightened awareness of interdisciplinarity. An oral historian is much more than a one-dimensional figure and to be good at oral history a person must also have significant skills in other areas such as communications, medicine, literature, etc. This also applies to illustrators; advanced, nuanced, and interpretative visual thinking requires broad multi-disciplinary knowledge. The principle of the illustrator as polymath recognises that illustrators often become experts in a range of fields due to long-running collaborations and the importance of understanding the subjects they are working on (Male, 2013). Scientists bring another range of competencies and approaches and there are clear crossovers in arts science and narrative medicine.

Dony and Van Linthout describe the process of remembrance as “partial and incomplete as well as creative because it consists in the juxtaposition of parts in order to (re) construct a coherent whole” (2010, p. 181). In many Graphic medicine comics and notably in this project, the ‘reconstruction’ is the creative process starting with the personal memories and then drawing on the knowledge, experience, and skills within a transdisciplinary team. This brings into question where the meaning or message originates. In *Negotiating Artistic Identity in Comics Collaboration*, Ahmed Jameel summarises that “meaning is constructed through cultural bricolage, ‘making do’ or piecing together one’s experience of culture with whatever is at hand” (2016, p. 182) and this might support the perspective of a shared authority. Critically, this project’s attempts to realise a shared authority was a way of approaching the participants’ position as a decolonised one. Here, we might think of the influential work of Eve Tuck, who seeks to interrogate ‘damage-centred research’ as ‘damaging research.’ Although her focus is on the experiences of Indigenous and African American communities, the effort to “depathologise the experiences of the dispossessed and disenfranchised communities so that people are seen as more than broken and conquered” (Tuck, 2009, p. 413) is relevant: the interviewees are more than their severe asthma. In practice, this ethos was difficult to realise, and this project does not readily escape the determining ‘frame’ of severe asthma as a dominating theme of the participants stories.

Although the attempt to ‘decolonise’ authority did not encourage more holistic life history engagements, it nevertheless had a creative and highly productive effect on the interview engagement itself. Two rounds of interviews took place: in the first, students worked in pairs or threesomes with one

interviewee; in the second round, one student returned to the patient-participants for follow-up with reference to visual development. The Project Team discussed the implications of deploying multiple-member interviewer teams and decided that it was necessary and productive to have both heritage-history *and* illustration backgrounds represented: their engagement with interviewees would appropriately reflect their areas of expertise, for example, illustrator questions relating specifically to visualisation.

It must be noted that no health experts were present during the interviews. This absence generated a unique inter-subjective dynamic. In her oral history research on military prostitution during the Allied Occupation of Japan, Michiko Takeuchi argues that ‘analysis of intersubjectivity is an essential aspect of interpretation,’ requiring interviewers to understand that who they are – their background, education, age, gender, and so on – all not only influence the interviewee; but they subtly and dynamically shape the “historical and socio-cultural nexus of power that was condensed in the interview space” (Takeuchi, 2015, p. 80). That each interviewee was presented with interviewers who were students, significantly younger than themselves, all yet to complete their degree studies, and expressly having minimal knowledge of severe asthma including the therapy, authority shifted significantly. As a result, the interviewees had to occupy the role of expert, their voices amplified to convey specialist knowledge, both medical and personal.

Stage 3 – Visual development

During this stage, students developed their own visual narratives within studio modules. Through an iterative series of discussions with the project supervisors and interviewees the visual narratives were progressively refined in a co-creative process. As far as possible the interviewee’s own words were used within the graphic narratives. Continuing support was offered via ongoing tutorials throughout the project. The illustrations were completed by June 2022.

The students were encouraged to experiment with different approaches and media and to demonstrate the synthesis of independent research as part of their visual development process. At this point, their developing authorial and creative identities came to the fore. In the introduction to *The Third Hand: Collaboration in Art from Conceptualism to Postmodernism* by Charles Green (2001) memorably describes artists as ‘thieves in the attic’ suggesting an inclination to find and adopt the authorial identity of others. To extend Green’s metaphor, the projects pedagogic approach encourages the ‘rummaging in dusty, dark rooms’ to discover and shine light on varied and inspirational approaches. However, the aim is to advance the student’s individual work beyond generic appropriations of current trends (a common criticism of contemporary illustration) and towards mature, informed, and original practices with the potential to contribute towards new understanding of illustration as a creative paradigm. That the project permitted the students to experience, recognise, and understand a shift from individual to composite subjectivity is hugely significant. Permitting insights from subjective readings or interpretations of a medical narrative can also release health professionals from the “obligation of teasing out the objective ‘truth’” (Williams, 2012, p. 26).

The comics act as a conduit between the interviewee’s lived experience and the readers engagement and, on one hand, the student’s artistic voices could be seen as relatively marginal to the authorship of these stories. On the other hand, the students artistic voice is central and has particular importance

to how the reader engages with and interprets the work – ultimately, “meaning is made and is contingent to the conditions of the experience, and the subjectivity of the reader” (Jameel 2016, p. 184). The illustrators’ creative signatures and developing skillsets bring a unique perspective and the representation of memories and emotion, are loaded with layers of additional meaning through the creative interpretation and adoption of visual narrative structures, techniques, and devices.

Broadly speaking, all three comics use a ‘before and after’ structure. This way of structuring graphic medicine is effective and commonly used in health advertising to communicate the benefits of new drugs quickly and persuasively (Horton, 2018), but to frame the student’s comics this reductively would be a misjustice to the complexity and nuances of work derived from the person-centred approach. Consider the following statement from Interviewee 2 who, in reflecting on the life-transforming efficacy of their treatment, historicises their experience as a narrative of innovation and whose moral value is given gravity through a reference to long-term technological change: ‘having lived through the 1950s with [asthma] and the treatment I had then to what I’ve had now, is so radically different’. In this one statement occurring halfway through the interview, the narrative trajectory of before-and-after reveals how personal historical meaning is generated and, in turn, how personal identity evolved. To be certain, the ‘before’ was not wholly bleak: despite an increasing dislike of school because of growing restrictions on activity such as sport attributed to asthma – all of which in the patient-participant’s own self-estimation, hindered their maturation – their working years were largely ‘normal’ until 2015-2016 when the condition returned with full force. Nonetheless, even as asthma retreated for a lengthy period, it was ever-present, acting as a key determining frame shaping the participant’s identity: ‘As far back as I can remember as being a youngster, I was blighted with asthma.’ Indeed, each of their life-stages from schooling, through work, and especially following the onset of severe asthma, were reflectively detailed in the interview in terms of strategies of hiding and coping: the avoidance of specific public environments and the regimentation of daily schedules and basic activities, much of which were structured to prevent disclosure to family and colleagues of the condition, which the patient-participant regarded with a mixture of shame and fear due to their inability to effectively and fully contain it.

In bringing attention to the interviewee-student’s narrative construction of their past, it is appropriate to call on Sarah De Nardi, whose work on affective communities in the context of war memory invokes the idea of ‘vernacular memory’. Articulated in the oral communicative memory practices of dis- or lesser empowered communities – in the case of Interviewee 2, disempowered by asthma – this kind of memory is dynamic and can be transformative of the understanding of one’s own historical identity, but also and especially for the audience – the students who will visualise and disseminate the knowledge shared – for whom this story is recollected, articulated, and performed (De Nardi, 2015). In this light, vernacular memory is strategic, memories directed expressly at influencing the students whose task it was to visualise and represent knowledge – a form of medical expertise – shared in the interviews. Recall here how the inter-subjective dynamic of the engagement is framed by the intern’s lack of medical or historical knowledge of asthma.

COMICS AND DISCUSSION

Comic one is a 16-page story told from the perspective of a mother whose asthma starts as a young child, progressing to dominate her life as an adult. Sudden, unpredictable asthma attacks disrupt her

life. Hospital becomes familiar. She becomes tired of not managing her life and tired of being a failure. Conflicting and damaging advice from doctors and nurses make her feel worse and steroid treatment lead to her gaining weight. She finds herself in a downward spiral.

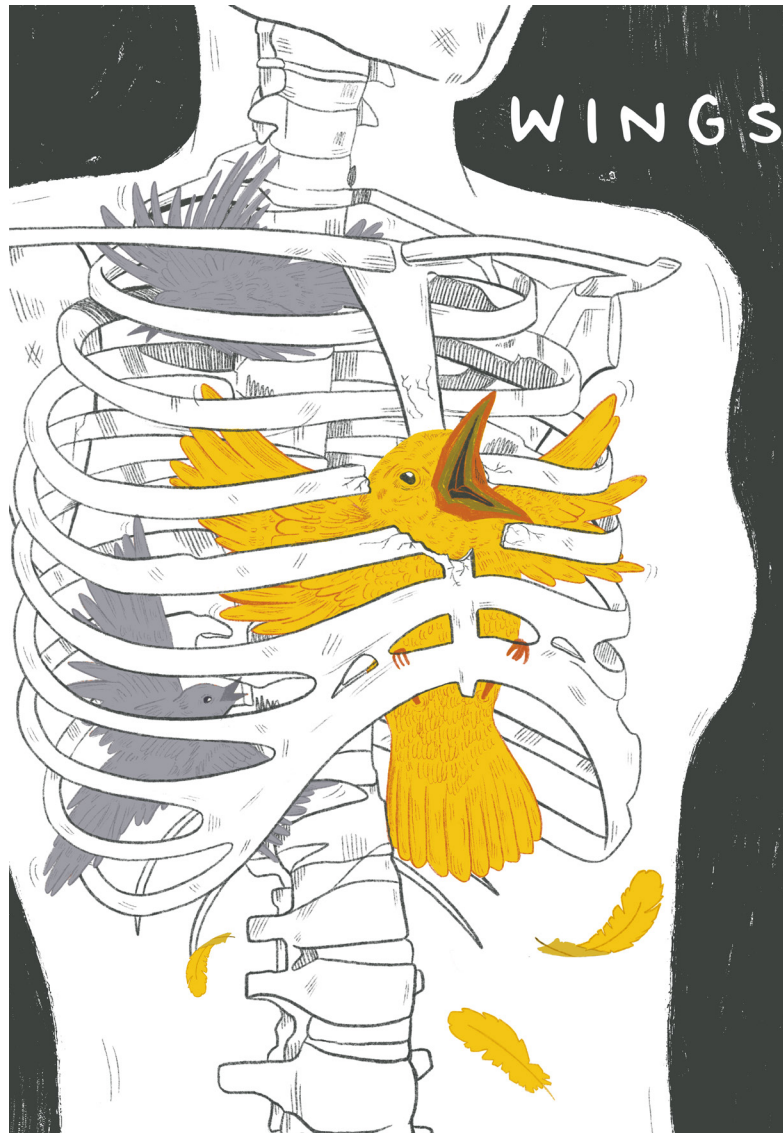


Figure 1: Cover illustration for *Comic one*

The comic uses a visual analogy of caged birds; birds that become fat on steroids and during bad asthma attacks are illustrated trapped and screaming in tiny cages or, as on the front cover, within the chest cavity, see Figure 1. Using metaphor and fictional elements allowed the creator to express emotions and abstract concepts conveyed in the interviews that might otherwise have been difficult to convey (Bowen and Max Evans, 2019, McNicol, 2019). In *Graphic Medicine and Radiology Nursing: Using Comics for Education and Stress Mitigation*, Esther Saltzman analyses *Mom's Cancer* by Brian Fies and notes how patient and family fear is emphasised through visual language using Frankenstein's lab as a metaphor (Saltzman, 2023). The author notes that some audiences may be surprised at how sophisticated comics can be at communicating information. Emphasising fear through metaphor may be an appropriate way to communicate or educate but it could also lead to confusion (Venkatesan and Murali, 2022) particularly if the original context of the visual sign trumps the significance of the intended

effect. It is a criticism of Graphic Medicine that imagery or fantastical elements may sometimes detract from the seriousness or clarity of the message. An element of fear and confusion seems appropriate for *Comic one* as these emotions reflect what the participants expressed and embodied in the interviews, and this, in turn may help to create a sense of empathy in the reader. At the end of *Comic one* the birds are finally freed when biologics unexpectedly, and massively, improve the patient's asthma. The use of the same metaphor to communicate the positive impact of the treatment should help to reinforce the impact of the intended message. A limitation of this study is that the interviewees were all super-responders and therefore the stories told are all positive affirmations of the value of the new treatment. There were no interviews with people who did not respond and therefore might have vastly different perspectives; this resonates with another criticism of Graphic Medicine comics which suggests a tendency towards trite or stereotypical representations of illness or that stories can be unrealistically hopeful or positive or alternatively excessively dark and traumatic (McNicol, 2015, Richardson et al., 2023). In this case the metaphor works well to communicate the idea powerfully without unnecessary embellishment using horror tropes, threat or fantasy, and is sufficiently original in implementation to (subjectively) avoid these pitfalls. See Figure 2.



Figure 2: Double page spread from *Comic one*

Comic two is a 32-page narrative describing a man at retirement age looking back on his problems with asthma throughout his adult life. The man's isolation and limitations, caused by severe asthma,

are strikingly depicted in black and white. It shows how he denied and hid his asthma from others until one day he was found by his partner during an attack. Despite his misgivings, his partner takes him to hospital. After admission to hospital, he is given biologics and a dramatic, beneficial change in his health occurs allowing him to retire. "I have the best life now," he says walking with his partner and dogs on the beach. The calm colours and images at the conclusion of the visual narrative contrast starkly with earlier, powerful depictions of the asthma sufferer being consumed by fire. The sense of much of his life being wasted by severe asthma emerges and how different it might have been if these drugs had been available to him sooner. See Figures 3 and 4.



Figure 3: Double page spread from Comic two

The idea that readers of comics will understand, engage with, and interpret sequential narratives differently has been widely written on by scholars and artists (Gravett, 2013, McCloud, 1994, Peterle, 2021, Tan, 2011, Sousanis, 2015). The comic form allows a non-linear approach to reading, and the gutters and spaces between panels require the reader to *fill in the gaps*. Normally this process happens naturally and unnoticed through the powerful cognitive process of *closure* (McCloud, 1994). An interesting creative device within *Comic two* is that chapter breaks have been used to create pauses within the narrative that instruct the reader to 'breathe', see Figure 5. This represents a sophisticated and nuanced method of breaking the 'fourth wall'; It is intended to amplify the involvement of the reader in creating their own unique understanding and engagement with the narrative through mindful reflection on breathing and personal health experience – if they have no problems breathing they may feel grateful or relieved; or they may think back to previous experience of pulmonary

infection if they are suffering from a condition at the time of reading they may feel empathetic to the narrator.



Figure 4: Double page spread from *Comic two*



Figure 5: Double page spread from *Comic two*



Figure 6: *Comic three*

Comic three describes the same participant's story as *Gasping* but in an entirely different way. A simple six-page booklet flooded with colour from wet, ink washes. This comic focuses on three key moments of the participant's life: from when they first experienced symptoms as a child, to the height of their asthma attacks, and then post-treatment where their quality of life is positively transformed. See Figure 6. 'Vernacular' medical knowledge was of particular importance to the illustrator and the colours used reflect and honour the patient's descriptions of their experiences, using the tones that the patient linked with their lived experiences: 'The good is yellow', responded Interviewee Two to the interviewer's question of colours that 'spring to mind...that represents how [you] feel': 'And purple is as dark as I can get without being dead, and that's how I measure it in colour'. The direct relevance of the patient-participants' self-perceptions to visual representation is clear. *Comic three* is noticeably shorter than the other two and simpler in its design. The concertina format allows it to be read as a single page. An important consideration when making illustrated health materials must always be the visual literacy of the intended audience. Using images can help to lessen the cognitive load when communicating health information and thereby aid in the communication of key messages (Arcia et al., 2019). By making health materials accessible there is more chance of them being useful to the people who need them the most. Materials with clear messages can be read by a wider demographic and this may be particularly advantageous to audiences with low health literacy including socially deprived, disadvantaged, or younger audiences. The simplicity of the booklet might make it attractive to clinicians. Qualitative research has shown that clinicians prefer simple, accessible language, written in lay terms for visual decision aids for asthma treatment and a clear preference for single-page materials during point-of-care discussions (Gagné et al., 2022).

Stage 4 – Returning the stories

The stories were returned to the original interviewees who had the opportunity to review the works and suggest any changes. Students and interviewees were asked to fill out a short participant feedback form as part of providing permission to release the artwork for wider dissemination. The form

included five questions:

1. How satisfied were you with the interview process?
2. How satisfied are you with the artistic outputs?
3. What, if anything, was most helpful for you?
4. What, if anything, did you enjoy the most?
5. Do you have any suggestions on how we could improve the process?

During their modules, the students wrote critically reflective visual research journals that documented the conceptual and visual development of their artworks. They were asked to complete personal assessment forms for their associated modules and to write a reflective paragraph about the experience. Reflections on the experience by staff, students and participants was overwhelmingly positive. A notable feature of feedback from both the students and the participants is how beneficial and enjoyable they found the actual interview. The first-hand interaction "*enabled connection on a much deeper level*" (student reflection) and provided the opportunity to ask specific questions linked to visual development.

Feedback from the interviewees was decidedly positive. "It was a great experience- well conducted by the students and it revitalised my memories of my asthma journey and made me appreciate more the benefits I have derived from (my biologic treatment) and how lucky I am." One interviewee indicated the most enjoyable aspect was "*being interviewed by the students,*" and continued "I was absolutely staggered by the quality of the students' work and never envisaged seeing such high standards and accurate delivery." In fact, all staff, and the two interviewees had descriptors that fitted with the reflection of being '*staggered by the quality of the output.*' A staff member indicated "*these are stunning, and so affective. The background colouring creates an almost visceral feeling, over which you then have these very short excerpts that paint entire individual stories, characterisations.*" Beyond the quality of the illustration the impact on the individuals concerned included a feeling of being "*recognised and heard*" and being able to use the final product to share the story with family and friends. The other individual found recounting the asthma journey positive for reinforcing the benefits derived from their biologic medication.

"Getting to conduct the interview and speak to the participant myself (...) was such a rewarding experience. It helped me have a real emotional sense of the transformation the asthma treatment has had on someone's life (...) The opportunity to ask questions, clarify points and hear their story brought the brief to life in a way that a written narrative would not have compared." ~ student feedback.

All four students indicated the training was enjoyable and well taught, and the accolades of the participants would suggest that this had been provided to a suitable level. The collaboration and cross disciplinary working featured in the reflections as a positive aspect of the experience, as well as providing the opportunity to apply illustration practice to new areas, opening potential directions for future careers. One student commented that the project was an "incredible experience" that they "would never have had the chance to do" if they had not come to university, another expressed "I've felt privileged to take part in the asthma project. It's hard to sum up in words the sense of excitement and confidence in the value of illustration this project has given me, and my values and interests have

really been understood and respected.” Another student’s feedback was equally positive: “This module has been an incredible experience... I think that involving students in conducting the actual Fresh Air interviews to use as a primary source was a fantastic experience and this first-hand interaction with the participant influenced my comic hugely.” The only negatives coming to light from students were the hours of work it took to produce the comics, significantly more than the 20 hours of participant time paid for, and how the inboxes of students filled up with email traffic from the project team. It is important to note that if these methods were to be used in a formal research study, that the funding would need to allow for the artists to have the time and freedom to develop original authorial artworks. The time required for this would lessen if experienced illustrators rather than students were employed.

GAINING FROM THE EXPERIENCE

The pilot materials have been shared with various stakeholders with widely positive feedback. Stakeholders included the participants, students involved in the project, people severe asthma, clinicians, academics, and pharmaceutical industry. People with asthma including the patient advisory group of the SHARP network (Djukanovic et al., 2018) have been particularly impressed by their potential to be used to inform patients, their families and their workplace or school. Equally they saw the comics as being a useful tool for educating doctors and nurses in primary and secondary care. Overall clinicians and leading academics were impressed by the way that the comics created a clear account of the emotional, social, and psychological aspects of biologic treatments for severe asthma. Clinicians noted some problems with the wording as the patients’ words were used verbatim, the clarity could be improved. One participant stated, “I didn’t need to take inhalers”, which referred to reliever inhalers. This statement could be misinterpreted as suggesting that all her inhalers could be stopped (including preventer inhalers) which may not be safe. In future work, clinicians should be given the opportunity to review the wording of any comics produced to ensure accuracy and safety of the messages before the comics are shared publicly as education resources.

The work was presented at the British Thoracic Society winter meeting (Jones et al., 2022). Staff from several pharmaceutical companies affirmed their interest in the comics; and following this project, one student’s artwork was licensed by a pharmaceutical company for advocacy and marketing and further development as an animation. In *Comics Arts*, Paul Gravett writes that “misery memoirs” of illness and tragedy may not be riveting reading for all (2013, p. 94), inferring that artists may repeat the misery memoir ‘formula’ to capitalise on suffering for self-promotion or personal gain. The student’s comics describe the life changing qualities of the biologic treatments, and it seems clear that as well as the participants, the pharmaceutical companies would stand to benefit from these methods. Although the value of comics to pharmaceutical companies is recognised within comics communities there is a noticeable reluctance to engage with this subject. This is reflected by a founder of the Graphic Medicine movement, Ian Williams, stating in an interview with Farthing and Priego, “you don’t really want to be dragged into promoting pharmaceuticals, because I find that one of the most tedious bits of medicine” (Farthing and Priego, 2016, Question 10). Williams suggests that comics with overly didactic messages are not as interesting or good as things that come from the heart – perhaps this is where the person-centred approach really makes a difference? Another consideration from comic creators may be the largely critical body of graphic ethnopathologies that reflect bad experiences or perceived “unethical tendencies and exploitative practices” of the health care industry,

particularly in the U.S. (Venkatesan and Murali, 2022, p. 40). Comics have a long history as an “anti-establishment, low-brow art form that has challenged the status quo” (Venkatesan and Murali, 2022, p. 40); creating work for drugs marketing purposes might be seen as antithetical to a comic artist’s *raison d’être*.

A FIRST-HAND ACCOUNT OF A MEDICAL RESEARCHER’S PERSPECTIVE

As a medical researcher working in the UK and in global settings, I have found two major problems, firstly that the research is not patient focussed but instead studies physiological markers, and secondly that communication of the results of the research to both patients and clinicians is not working. As a result, expensive research is ineffective, and patients needlessly fail to get the life changing and lifesaving treatments that are available.

Long-term conditions have a range of effect on the sufferers, but research often focusses on elements of a disease that are easy to measure, such as blood tests, but are often irrelevant to the lived experience of those affected. For example, people with asthma do not care about the blood eosinophil counts, but do care about its effects on work, social life, and mood. Without the patient’s perspective, we are missing an important element of understanding the impact of a disease and the benefits and harms of a treatment.

While the findings of medical research need to be understood by the medical and patient communities, getting messages across to the populations affected is both important and challenging. Research findings are conventionally disseminated through conferences and papers in scientific journals. However, the large numbers of people who are affected by diseases, such as severe asthma, do not get reached by such methods. They have much to gain from understanding the research and how it applies to themselves. Health professionals too often miss out on research findings because of their busy lives and messages failing to reach their target. As a result, many patients do not get the best treatment with resulting losses to patients, their families, the health service, and the economy. We need effective messages understandable to lay and professional audiences. Too long we have relied on dry scientific publications to share our understanding of how patient suffer from disease and how treatments can harm and help them.

By using visually exciting materials, we can reach wider audiences, to quickly and effectively share messages, including conveying the emotional impact of a disease and its benefits / harms of treatment. Our long-standing collaboration with the illustration department at Plymouth University has helped produce some major educational achievements which cut across literacy and language barriers. In this study, severe asthma comics illustrate graphically how major the impact of asthma can be on patient lives and how novel treatments can create huge benefits to their quality of life. Comics produced using these methods could provide a way to disseminate medical research findings to populations affected, healthcare professionals and indeed regulators, to help them understand why certain treatments are worth paying for. Without effective communication of relevant research to the right people with a clear message, which is easily and quickly understood, important research is misunderstood and wasted.

CONCLUSIONS

The pilot comics demonstrate how personal stories of people with lived experience of severe asthma

may be sparked, captured, and given greater context through our novel, collaborative oral history-visualisation approach. With emphasis on change over life courses, these stories – verbally remembered and visually rendered – powerfully communicate the emotional impacts of severe asthma and the profound improvements after biologics. By embedding the creative work within university modules, we were able to facilitate a rigorous and supportive creative environment that enhanced the co-creation process through knowledge exchange and research informed teaching.

The comics demonstrate a shift in narrative authority towards the interviewees and the reader, and away from the artists who had no medical expertise or the medical experts who had no lived experience of the disease. Vernacular medical knowledge was used to capture unique perspectives and students' active participation in the interviews was of critical significance in providing new insights into the lived experiences of medical intervention.

The student's individual artistic voice came to the fore during the visual development stage and the building of coherent and engaging narratives. That part of the method encouraged the students - gave 'permission' - to explore creative, individual approaches, thereby releasing them from a strict obligation to objective truth was important, allowing them the space to experiment and evolve their practices whilst gaining crucial understanding and experience of intersubjective and transdisciplinary ways of working. Working on collaborative and interdisciplinary projects can help to develop illustrators' understanding of the breadth of contemporary practice as well as the value of comics and visual narratives as a research method and the wider impact these works can achieve.

The project supports the value of illustration practice for interdisciplinary research by demonstrating a method that could effectively be used in a formal research study. For use in clinical settings the materials made using this method would need to be validated via consultation with clinicians and patients. Further consideration of the audience in the development process could be helpful in determining the style of the comics, particularly audiences with low health literacy.

FUTURE PLANS FOR CREATIVE ACTIVITY

The comics are being shared through patient and professional organisations and their conferences. Funding is being sought to develop the comics in more people with severe asthma in several European countries through the SHARP network. We are also exploring their use in different disease areas for example innovative treatments for young people with cystic fibrosis and for biologic treatments in rheumatoid and other severe diseases.

We plan to continue exploring novel research methods using illustration in collaboration with history and health. Part of this work will be to explore different methods for visualising health histories such as live scribing, animation, games and pop-up books and further analysis of the intrinsic qualities that these processes embody and that may have value in the context of health.

DECLARATION OF INTEREST STATEMENT

- John Kilburn, Darren Aoki, Alice Inman, Isabel Keen, Devon Tipping, Anais Lichtensztejn and Danielle Glover declare no conflicts of interest in the study.

- Joseph Lanario declares no conflicts of interest related to this work but has received research funding for other unrelated projects from AstraZeneca and GlaxoSmithKline.
- Rupert Jones declares no conflicts of the interest in this study but has received research funding for other unrelated projects from AstraZeneca and GlaxoSmithKline and OPRI.

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Figure 7: Image from *Comic one*